

ENABLING SERVICES METHODOLOGYWORKSHOP FINALREPORT

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Enabling Services Methodology Workshop

Final Report

I. BACKGROUND

The Lewin Group was commissioned by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), Department of Health and Human Services to help ASPE develop a research agenda on issues related to enabling services. The focus of the effort included: identifying questions practitioners, payers and policymakers have raised regarding enabling services and determining potential approaches to addressing these questions.

This report reviews findings and raises implications of these findings for a potential research agenda. Its intent is to specify both short and long term strategies to answer key questions and to identify methodological approaches and concerns. This effort and the various exchanges with both a workshop panel and the Project Officer resulted in a set of issues that may warrant further attention. While the priorities for specifying a research agenda are not clear, we attempt to identify areas where new information may help clarify the key policy issues and options related to support for enabling services.

Enabling services, those services that assist individuals in obtaining necessary health care, have been an inherent component of the Public Health Service's mission to provide health care to low-income vulnerable populations. The 1994 Health Care Reform Debate raised concerns regarding the organization, provision, and financing of enabling services. To help better understand the issues at that time, the Office of the Assistant Secretary for Health commissioned a study, "Enabling Services: What We Know and What Remains to Be Learned," conducted by MDS Associates which examined the types and costs of enabling services provided by programs funded under the Public Health Service Act. This initial examination of enabling services resulted in two important findings: 1) available data show wide variation in expenditures per user for enabling services; and 2) current reporting and accounting systems are not easily manipulated to provide comparable data on enabling services within and across programs.

Since the publication of the 1994 study, changes in the financing and support of health care services for vulnerable populations have renewed concerns regarding what many perceived as reduced financial support for enabling services. These changes also appear to have an impact on the capacity of those who traditionally provide enabling services to vulnerable populations. For the most part, little additional research has been completed to provide more answers to the questions raised in 1994 or to document changes since that time.

Among the key changes that are anticipated to affect enabling services are those arising from the expansion of managed care, particularly in public programs such as Medicaid. These changes, made by state programs, may affect the definition of benefit packages and the types of payment mechanisms used. As states and the health plans with which they contract make decisions, questions are being raised about whether to include enabling services in the benefit package, how to pay for the (fee-for-service, capitation, etc.), how much to pay, and who should provide such services. In addition, the changes in public programs have also created new challenges for safety net providers who are often the primary provider of enabling services to vulnerable populations. Unanswered questions about enabling services continue to affect policy discussions as currently evidenced in the deliberations at the federal and state levels over how best to design new efforts for children under the State Children's Health Insurance Program. Finally, as more private sector providers participate in public programs, concern with how to provide and finance enabling services is further heightened.

In the context of these developments, we identified five key areas of issues regarding enabling services. Each may represent issues for policymakers, program providers, payers, and/or researchers.

- **Defining enabling services.** The issue of what constitutes enabling services varies depending on one's vantage point. We attempted to capture this variation and examine if there are indeed common definitions of enabling services and what delivery mechanism (packaged or individualized) is preferred by various groups such as providers, consumers, and payers. The need for an "operational definition" of

enabling services as they apply to health care rather than to broader human services is particularly critical for setting a research agenda so that one can determine what the phenomenon called enabling services is and how to examine it.

- **Determining the need for enabling service.** Determining the needs of an individual for any given service or set of services may be complicated by the availability of services, and what is known about their effectiveness. From the perspective of policymakers and payers, it may be more important to be able to define needs for groups or populations rather than on an individual basis. Individual needs are usually more critical for the program or service provider. In either case, issues of intensity and frequency also need to be addressed within the context of individual or sets of enabling services. Research may take either perspective depending upon the particular question being addressed.
- **Defining enabling service providers and delivery systems.** The providers of enabling services and how enabling services are delivered are changing. Traditionally enabling services were considered the primary domain of those providers who were defined as the “safety net.” The advent of integrated health systems, disease management companies and approaches, as well as the increased participation of previously private providers, in serving vulnerable populations have influenced changes in the mix of providers and delivery systems. The expansion of managed care within public programs also increases the role of contracted health plans in deciding who the providers are and how enabling services will be provided. Central questions to be explored include: who is counted as a provider?; who defines providers?; and what are the implications for the type of delivery mechanisms that are needed?
- **Paying for enabling services.** Currently, enabling services are paid for in a variety of ways including: inclusion in public and private insurance benefit packages; specific publicly and privately financed programs; and the creative use of existing funds. This patchwork is often not understood by either providers or patients and may result in less than optimal and appropriate approaches to the provision of enabling services. Policymakers need to understand how the current financing systems work and their

implications in order to improve access and **efficiency**. Providers and patients need to understand the financing in order to improve their ability to access the systems of care available. The increased role of managed care plans in paying for enabling services through capitated arrangements both increases the need to understand the payment approaches and complicates the **ability** to conduct studies in this area.

- **Identifying cost and effectiveness of enabling services.** Information on the cost and effectiveness is very limited and difficult to obtain, although there is a general belief among those servicing or addressing the needs of vulnerable populations that both individual and packaged enabling services are effective. However, lack of data on costs and effectiveness of enabling services has been cited as a major barrier to financial support for these services. Answers to questions in this **area** are desired by all the various groups we have identified.

These five issues provide the basis for exploring the more detailed questions and concerns of various stakeholders and for the identification of areas for potential research. Selection and better definition of a research agenda requires **defining** criteria for determining priorities, identifying data sources and limitations of available data to answer specific questions, and consideration of methodologies and approaches that might provide practical next steps.

The Lewin Group identified and explored the set of key questions in each of these five issues through: a limited literature review; a series of interviews conducted with individuals representing perspectives of consumers, providers, payers, and policymakers; additional interviews and literature reviews on disease management as a particular interest identified after the draft report and through a dialogue **from** a roundtable discussion involving expert panel members. Section II of this report provides a brief summary of key findings from the data gathering process and addresses research implications presented by our analysis. Section III identifies the specific types of questions raised by various stakeholders. These questions help guide the proposed considerations for a research agenda describes in Section IV.

II. SYNTHESIS OF FINDINGS AND THEIR IMPLICATIONS

This section briefly summarizes information from the extensive interviewing efforts and a roundtable discussion conducted with individuals representing perspectives of providers, payers, advocacy groups, researchers, and policymakers. Results from the interview phase of the project were used to inform the roundtable discussions and were organized around the five key topic areas. The literature review provided limited new information, although a number of studies were identified by roundtable panelists who have been asked to provide more detailed information. An additional effort was made to examine the literature on disease management and to interview selected individuals to explore the role of enabling services in disease management approaches. In this section, results from both interviews and the roundtable are reviewed. •

Issue 1: Defining Enabling Services

The starting point of this project was the previously mentioned descriptive study by MDS Associates, Inc. that defined enabling *services as “services that facilitate access to medical care and/or support individuals in managing medical conditions.”* This definition resulted in further specifying a set of five core enabling services (case management, transportation, outreach, patient education, and translation/ interpretation) and additional enabling services (information and referral, environmental risk reduction, community education, child care, housing, food, and clothing assistance). The MDS study concluded that there were unresolved **definitional issues** that formed the basis for further discussion in our interviews and the roundtable.

◆ Exploring the boundaries of the definition of enabling services

Interview respondents suggested that the **definition** of enabling services should be broadened to reflect not only medical care, but also a set of non-medical services that address the social needs of a population. There was general consensus that this broader definition should include assistance in assessing non-clinical related services (e.g. social services, housing, etc.). While there seems to be some agreement that there is a need for a broad definition of enabling services, there is still a lack of consensus on the resultant range of services. Additional services identified by respondents, outside of the core and

additional services previously identified in the MDS paper, include: care coordination; behavioral/mental health services; assistive technology/home modification/DME; nutritional counseling; crisis services/residential behavioral management; respite care; and homemaker assistance.

An additional refinement to specification of enabling services was the need for explicit policies that support or enhance obtaining services. These include: assistance to families/family support services; paid family leave; flexible work hours; and support to assure that services are appropriate (e.g. cultural competence training for providers, patient reminder services/24 hr. advice lines, broker assistance/ systems navigation services, indigenous outreach workers).

The basic definitional concerns reflect the need for a common approach for how enabling services is conceptualized. The process for arriving at a common framework has implications for research issues that must be addressed. Roundtable members proposed an outcome-based research criterion for enabling services where the focus is on the benefit afforded by the provision of enabling services. This approach would result in a definition of enabling services as *“any **service** that allows the individual to take maximum **benefit from** health services received or that has a **beneficial** impact on outcomes.”* Such an approach reflects the World Health Organization (WHO) definition: “Any service that is necessary to improve access to or generate benefits from the services provided (is an enabling service).” This type of outcome-based definition of enabling service would help define a research approach that focuses on determining how positive outcomes are achieved, including the mix of services and the efficacy for enabling services.

While a broad definition of enabling services may solve some problems, it also created concerns expressed by the Roundtable members that were not resolved. One example of definitional concerns was applied to therapeutic horseback riding as a potential enabling service. Issues related to how to classify and how to assess benefits were raised with panel members disagreeing on its inclusion. Others raised questions regarding whether to include these types of services citing their limited beneficial impact for a significant portion of the population and/or how to classify such services. In any case, there are

implications for potential research that address the efficacy of a given service and what the determining factors for inclusion of an enabling service in a benefit package might be.

As a result of the various discussions and follow-up meetings with ASPE and HRSA representatives, the boundaries of what is included in the definition of enabling services is defined by the following: enabling services are those services that provide the link between medical and social services but do not include those social services.

◆ Examining bundled vs. individualized enabling services

A highly related issue to how to define enabling services is whether to consider enabling services as a package or individually and whether the type of arrangement impacts the benefit achieved from those services. Both interview and roundtable respondents had mixed opinions on whether enabling services should be considered individually or as a package. **The majority** argued for enabling services to be considered individually on a needs-based system.

The reasons identified to support consideration of enabling services **individually** include:

- Individual consideration of services takes into account the unique needs of the person;
- Concern that inappropriate use or over-utilization of enabling services may occur if a client can choose from a package of enabling services;
- It may be easier to contract for services and provide assurance that those individual services are being provided;
- Reimbursement may be **simpler** when services are considered individually. Payers, especially managed care plans, may be less willing to pay for (or may place limitations on) a bundled set of services that would have to consider relationships of individual services within a package.

The reasons identified support consideration of enabling services **as a package** include:

- Packaging of enabling services typically mirrors the nature of problems that clients encounter. Problems associated with accessing health care services usually present themselves as a “cluster of problems” and require a cluster of services;
- Availability of a set of services may allow for better selection by clients of enabling services that are needed in both the short and long term;
- The packaging of enabling services may provide a better basis for the calculation of rates than having to do so for individual services;
- Conducting research on quality and cost-effectiveness is viewed as enhanced than if services are examined individually since it is difficult to separate out the unique contribution of an individual service from the effects of the full array of services provided.

We elicited arguments on both sides of this issue. Besides the overall argument of whether enabling services should be bundled or not, questions were raised regarding the relationship of a specific bundling approach to the ability to conduct research and whether or not such considerations should factor into defining a research agenda. While a bundled approach may be more conducive to research, there is concern as to whether this is best from other perspectives. As with several other issues, there may be different incentives based on whether the concern is one of a service provider, payor, patient, or researcher. Thus, there is a need to determine the criteria for defining the basis by which enabling services are bundled should be used, and who should make those decisions.

Several different strategies were suggested in the roundtable discussions. The first approach was to take a “usual” versus “enhanced services” dichotomy as the criteria for separating out services for comparisons. Such an approach would examine the common patterns of services that are offered or provided together and group them. Other services that tend to be offered with less frequency or for which specific patterns cannot be discerned would be treated individually. A second suggested approach was to consider the type of medical condition or factors such as demographics as the basis for bundling services versus an individual needs assessment process. In both cases, there are

implications for how researchers determine the basis for comparisons among sets of enabling services.

To the extent that policymakers and programs employ different methods of bundling, research efforts will be more complicated. This is particularly true in developing outcomes studies to show the effects of enabling services. Ultimately it would be desirable to have empirical evidence to use for bundling decisions. It was clear, however, from discussions, that a key preliminary step might be to identify how enabling services are typically organized/bundled for delivery and from that analysis develop a **typology** of sets of services for comparison.

Issue 2: Determining Need/ Approaches to Determining Need

Unmet needs for a wide variety of services were identified in both the interviews and roundtable discussion. The list of services for which informants felt there were generally needs across populations included: respite care; child care; case management; family support services; culturally competent outreach, transportation in rural areas; assistance with applying for health insurance; assistive technology; coordination with Medicaid, WIC and other programs; homemaker assistance; interpretation/communication services; parent support services; and patient education.

The rationale underlying the views that there is a great deal of unmet need for enabling services, however, was not clear. A set of reasons for unmet needs was given, although neither methods for determining unmet need nor databases to support specificity of these needs were identified. The reasons cited for unmet need (and availability) of enabling services include: the lack of funding; unwillingness to offer services due to lack of demonstrated effectiveness; lack of availability of services; cultural and linguistic barriers to accessing those services; lack of understanding of enabling services among managed care organizations; inability to distinguish enabling services which may be blended with general services; and a lack of providers to deliver the services.

◆ **Determining Need on an Individual Basis**

When needs are determined on an individual basis, an important factor is ensuring that an appropriate focus is used for making the determination of need. While providers assume that they know what services are needed, research suggests that this assumption does not always match the individual needs of the client. Respondents pointed to the tendency to diagnose needs “from afar” One panel participant indicated that a NIDA sponsored study showed that only 10% of those people that NIDA identified as having a substance abuse problem actually self-reported that they had a problem. As a result, a key concern to which researchers must be sensitive is that of who is representing the individual’s needs: the client, payer, or provider. It is anticipated that different needs might be identified based on who makes the determination. In other instances, patients or clients may be much more aware of their needs.

In many cases, the payer may set the rules or basis for determining whether to provide a specific service using the concept of “medical necessity” as the basis for willingness to approve and/or pay for a service. Lack of evidence as to the efficacy of a particular enabling service complicates the ability of the person making this determination to decide whether to approve a given enabling service. As a result, case managers or medical providers are usually left with the need to make individual assessments based on their own views rather than empirical evidence or good guidelines. Understanding of “what works” could contribute to more informed decisionmaking.

The implications of various processes and decisions and what the implications are for enabling services that are provided is a question that requires empirical research. There is a general concern that if need is determined on the consumer level, the result may be a demand for more rather than less services while if payers dictate need, there will be less services. However, studies have found that concern with overutilization by consumers when they are the decision-maker may be groundless. Panel participants suggested that some studies show that when consumers determine need by selecting from a menu of services, they use only what they need.

♦ **Determining Need on a Population Basis**

When needs are determined on a population basis, accurately estimating need (or demand) for enabling services becomes central for resource planing, the calculating of capitation rates, and determining service packages. We did not identify specific approaches that are currently in use and therefore cannot determine whether valid approaches exist. Discussants suggest that there is a need for processes that can be consistently applied and that to the extent these do not exist, developmental efforts might be required. These processes might include both methods to identify needs on a broader basis for planning as well as for individual assessment.

Related and unresolved issues raised in our discussions include the extent to which needs assessment processes are dependent upon case-specific assessments. To the extent they are, a person must present at some setting before needs for enabling services are determined. However, some studies suggest that there are a number of individuals in need of enabling services who do not enter the delivery system where need for enabling services are determined. Examples were given of situations where population needs are essentially what is in a benefit package and therefore individual needs are only addressed in the context of that benefit package and the specified services. One example given by a Roundtable participant suggested that a particular set of enabling services were only offered to individuals enrolled in SSI. Their organization, however, estimated that nearly 25 percent of women and children not enrolled in SSI were also in need of such services but the managed care organizations (MCOs) did not identify these needs because the individuals were not eligible for the services.

Issue 3: Defining Enabling Service Providers and Delivery Systems

The changing provider landscape for enabling services has implications for not only identifying providers, but also identifying what information they require to make decisions on whether and how to provide enabling services. As managed care organizations become increasingly involved in enabling services, the question of who is considered a enabling services provider is not as clear cut. Issues raised included:

whether or not a health plan itself is the provider; whether the provider is whoever gets paid for providing the service; or whether it is whoever has a contract with the purchaser.

Providers can exist at many different levels of classification: individual level (e.g. case managers); specialized providers (e.g. special population focused providers and disease management companies); and providers who offer a comprehensive set of services (e.g. community health centers). Providers can also vary depending upon the population that is being served. As one respondent remarked: “In a substance abuse population, the criminal justice system is becoming a provider.”

The main concerns with defining who providers are and differences in the delivery systems for enabling services are more related to questions of what differences there are as a result of the provider and delivery system. These questions include some of the following. Are there different utilization patterns and results if enabling services are contracted out or not? Do costs and/or effectiveness vary? What role do safety net providers who have been traditionally providing some of these enabling services have and how is this changing? Is there a system of services or are they provided as a “patchwork” that requires health care providers and consumers to manipulate the system in the best way they can?

Given the changing nature of providers and delivery systems, an approach is needed to classify providers and delivery mechanisms into a logical typology. In order to answer the questions of who is considered a provider, what are the appropriate delivery mechanisms, and does it matter, research identifying the universe of providers and those characteristics across which providers can be grouped are needed. The roundtable participants raised concerns for a commonly agreed upon approach but recognized that initial steps might be to examine the provider and delivery system on a state by state basis where managed care contracting, especially within the Medicaid program may help define the parameters. Another area that was identified was the need to identify and understand what regulations exist concerning requirements for how services should be provided: by primary care provider or specialist contracts versus “carve-out” type services.

A clear **typology** of providers might provide an opportunity to link and exchange information between different providers, especially state and public/private programs. This issue becomes especially important as the range of providers who serve vulnerable populations expands. Establishing a feedback loop among provider groups may foster development of standards and an outcomes-based approach for enabling services.

Issue 4: Paying for Enabling Services

State and federal government agencies assume a major burden of paying for enabling services through **Medicaid/Medicare**, various block grants, and special programs. At the federal level, in addition to the more general financing mechanisms of Medicaid and Medicare that operate as insurance programs, funding often reflects **specific** individual programs that provide support for entities that serve a given population. These programs include such grant programs as the Community Health Centers program, the Maternal and Child Health Block grants, Substance Abuse and Mental Health Block Grants, and various sections of the Ryan White Act. The individual funding streams contribute to a patchwork of financing which is generally directed to a specific population and challenge those serving various populations to determine how to support their clients. Many **find** that this approach creates barriers to developing rationale systems of enabling services.

Research that focuses on identifying who pays for enabling services needs to capture the changing landscape of who pays as well as how enabling services are paid for. For example, as public insurance (Medicaid, CHIP) programs expand, it is expected that the role of block grant programs and other gap filling special programs is expected to change. It is also expected that changes in reimbursement such as the gradual elimination of the Medicaid cost-based payment of federally qualified health centers (FQHCs) will have an impact on the ability of FQHCs to support enabling services they have traditionally provided as part of the FQHC set of services. Research on the implications of changes in federal programs on the availability of enabling services is needed to determine what is happening and how changes need to be addressed.

An identification of the criteria used for determining what enabling services are paid for is an important research consideration. With the increased role of managed care

organizations in the payment and delivery of health services, there is a need to better understand the selection criteria used by health plans to support enabling services. Respondents expressed differing views as to whether or not managed care has a positive or negative effect on the availability of enabling services. There are both incentives and disincentives to pay for enabling services that are generally reflective of the overall concerns about whether or not managed care is about managing costs or managing care.

Research needs to address the issue of how the increasing shift to managed care and especially to **capitation** affects the availability and utilization of enabling services. Managed care organizations ‘typically provide/pay for transportation, case management, patient education, and translation services. Identification of what is involved in the decision-making processes to pay for these services versus others is important to understand. Other important research implications include: an identification of “medical necessity” in the context of health plans; what types of risk adjusters are needed to minimize the negative consequences of providing enabling services; and potential for expanding the availability of enabling services from Medicaid populations to commercial ones.

Issue 5 : Identifying Cost and Effectiveness of Enabling Services

There is very limited information on the costs of enabling services. Many of those we interviewed indicated that costs issues are particularly difficult to address because the costs of many enabling services are typically incorporated into other service costs and therefore cannot be easily separated either as individual enabling services or as a set. There is general agreement, however, that there is considerable variation in the costs of providing services and a need to articulate different components of costs such as the process costs (e.g. “amount of time devoted to case management, identifying providers, making arrangements,” etc.) from other service costs. Other issues that are particularly **important** to policymakers and payers are the identification of the things that affect costs such as economies of scale and the need for certain **infrastructure** supports that vary depending on their source and who pays for that support. Examples of infrastructure support may be computers and related information systems needed to support case

management activities. Further the issues of costs need to be examined both in terms of short and long term costs and benefits.

Determining effectiveness is an even more difficult proposition. While many respondents were convinced that the provision of enabling services was cost effective and resulted in positive outcomes, there was a lack of evidence to support this assertion. Given the scarcity of information that exists on costs and effectiveness for enabling services, roundtable members suggested a focus on determining *what* evidence different stakeholders may need or want concerning enabling services in general, beyond just cost and effectiveness. This approach has implications for the kinds of research questions that are necessary to ask and answer.

III. Identifying the Questions Regarding Enabling Services from the Perspectives of Various Stakeholder Groups

The interviewing process and Roundtable helped to define questions about enabling services from a variety of perspectives: policymakers, public programs, providers, managed care organizations, purchasers, and employers. While the specific questions of each group might differ, five sets of questions emerged that can help inform and direct a research agenda. Approaches to addressing some of these concerns are described in Section IV.

◆ Proof of efficacy required to demonstrate accountability

A key question, albeit asked for different reasons, is **what enabling services contribute to or result in improved patient outcomes?** As an enhancement to medical care, enabling services are viewed as a strategy to help improve the outcomes of the medical care. **Which enabling services help get people into care? Which enabling services contribute to their continuing care (compliance)?** In general all stakeholders are looking for answers to this question so that the most appropriate services are provided. The answers take on greater significance as decisionmakers who determine what is paid for seek information to determine whether to provide such services either within a benefit package or in making individual patient decisions.

Members of the Roundtable indicated that it is important to obtain information on both the contribution of individual services and bundles of services. The key underlying question is to determine what enabling services provide positive results. This area is seen as very complex and probably requiring multiple levels of studies to provide the range of information needed to make decisions and to choose among alternative approaches, to achieve desired objectives.

◆ Understanding the costs of providing enabling services

A major issue in deciding whether to offer enabling services is the lack of adequate information to address the questions of **what do enabling services cost?** There are a myriad of issues involved in answering this question and other related cost questions. Understanding the costs of enabling services includes:

- What is a unit of service for a given enabling service?
- What is the per patient cost of an enabling service?
- To the extent that a set of enabling services, rather than an individual service is the usual pattern, what are the combined costs of services?
- What are the costs of offering a particular enabling service (investment costs, operating costs, etc.)?

The lack of adequate data has made it particularly **difficult** for stakeholders such as health plans to determine how to cost enabling services. Policymakers cite the lack of information on costs and utilization as a barrier to considering how to **incorporate** enabling services in programs. Current “**capitation**” for enabling services or considering of enabling services in a **capitated** rate are often based on very limited information or best guesses. As a result, the debates and negotiations between payers (Medicaid, health plans, etc.) and providers (particularly traditional safety net providers) are **difficult** and perceived as frustrating by many involved. There is a need for fundamental information to build up a basis for costing enabling services. Concerns include **defining** the number of FTEs needed to provide “X” units of enabling services; **methods** of separating the cost of enabling services from other service costs; and approaches to identifying the direct and indirect costs of enabling services.

◆ Enabling services as a mechanism to attain goals

As health plans enter into contractual relationships with States for Medicaid populations, the plans may require information on how enabling services can assist them in meeting their contractual obligations. Public programs are beginning to stipulate performance goals as part of their contractual agreement with health plans. For both health plans and the public programs, information on how enabling services can be used as a means to a defined goal becomes centrally important.

For public purchasers, such as Medicaid/Medicare and CHIP, the importance of linking service provision to outcomes allows for greater accountability to legislators. **Knowing**

the “bureaucratic risk” attached to not funding enabling services can also assist public purchasers in identifying those services with the most immediate payoff, in terms of community impact, and how those services impact utilization patterns. For other public purchasers, such as employers, the provision of enabling services may be linked to their goals of a low employee absenteeism and turnover rate. Better information is needed to help make an argument for the “value added” of enabling services beyond health outcomes.

- ◆ Data elements and infrastructure needed to monitor cost , effectiveness, and utilization

Identification of data collection approaches and infrastructure needs for enabling services are highly related to the ability to address the issues of cost, effectiveness, and utilization of enabling services required by most stakeholders. Almost all stakeholders recognize and are concerned about the lack of data on enabling services. However, how to solve the problem and **particularly** where to start is not clear. On the one hand, barriers identified by various stakeholders to supporting or providing enabling services generally include the lack of data on costs, effectiveness, and utilization. On the other hand, the ability to conduct research and answer key questions regarding enabling services is dependent upon the availability of good data. Specification of a minimum set of data that might begin addressing the current void needs to be considered in light of current data barriers. The research agenda proposes a starting point to begin this process.

- ◆ Patient satisfaction and quality monitoring information

Respondents agreed that there is limited use of tools to monitor the quality of enabling services and that there is no system that documents the information needed to measure quality and satisfaction. All stakeholders need information on consumer satisfaction gathered through valid surveys as part of their regular way of doing business. The issues of enabling services might be part of such satisfaction surveys.

The quality of enabling services can be measured across many dimensions: access, choice, and richness of program. Research conducted through consumer surveys, focus

groups as well as building on State/Federal monitoring processes could provide a Way to measure whether both access and quality goals were being met.

The following matrix provides examples of the myriad of questions that are of concern to various stakeholders in these four areas. It is not meant to be exhaustive but rather indicate the large number of questions and the areas where the concerns cut across various stakeholders. The range of questions can also help to begin fleshing out some of the details of potential studies and/or be used as part of a research announcement to support studies on enabling services.

Exhibit 1: Examples of Types of Information Needed By Stakeholders

Stakeholders	Proof of efficacy	cost of enabling services	Mechanism to attain program contract goals	Data elements/ infrastructure to monitor costs & utilization	Patient satisfaction & quality monitoring information
Public Programs	What enabling services improve access? Assure compliance? Which population groups need which services?	What are the costs? What are the best approaches to providing these services? What are the payment sources?		What are the costs & infrastructure needed? What are immediate payoff and impacts on utilization patterns? What reporting should I require?	What is the association between enabling services and customer satisfaction? How do enabling services affect quality?
Policymakers	What works? What should be included in funding?	Who is paying? What are out of pocket costs? What information can be generated by comparing cost data across states, programs approaches?	What approaches will encourage providers and plans to offer enabling services? Are grants or financing the best ways to fund? What should be included in performance	What is the burden and infrastructure needed to monitor and collect information on immediate payoff and utilization patterns? What reporting should I require?	
Providers	What works? What are the best ways to provide certain services? Does it help the efficacy of other services?	What are the direct and indirect costs? What investments are needed? Is it better to subcontract?	How do enabling services assist in assuring compliance?	What data should be collected? How can it be analyzed?	Are our patients more satisfied? What affect is there on quality? On attracting and keeping patients?
Purchasers/Employers	Are there certain enabling services that should be in our benefit packages? Why? What are the implications for access, quality, and choices?	What are the costs ? Can they be predicted? On what basis should we pay? What is the relationship between enabling services & employer costs	How can linking service provision to outcomes allow for greater accountability to legislators?	What do we need to put in managed care contracts?	What are the issues for patient satisfaction? What do employees want?
Health Plans	What works to get better outcomes? Save money?	What are the costs? What types of capitation rates are appropriate? Who uses them?	How will providing enabling services help in meet my contractual goals for enrollees?	How can MCOs guard against inappropriate or over-utilization of enabling services?	Does offering certain enabling services provide a competitive edge? Are our enrollees more satisfied?

IV. CONSIDERATIONS OF STRATEGIES AND APPROACHES TO ADDRESSING QUESTIONS ABOUT ENABLING SERVICES

The focus of this section is to articulate a strategy to collect more detailed information on enabling services and to begin address the types of research questions raised by the work group and others. Currently work that relates to enabling services is often indirect and buried within larger efforts and under the auspices of a variety of programs and agencies. There is a need to both capture current work and to focus efforts in order to address the types of questions and concerns discussed earlier in this paper. This section defines a starting point that might provide this focus and the basis for identifying a selected number of studies that might be developed and funded. It is clear from our work and discussions that there is a need for more specific information on enabling services as well as efforts that address some of the fundamental questions regarding enabling services.

Questions to be addressed reflect a prerequisite for a common definition of enabling services and/or a way to look at such services. This common approach would then facilitate efforts to identify the current state of enabling services being offered, who is receiving the services, who is paying for and/or financing these services. The current environment is one of some confusion, with different stakeholders considering enabling services in different ways; with payors using different strategies; with providers offering different mixes of enabling services; with customers unsure of what is available or how to access services; and almost no information on effectiveness of any of these services:

We believe that both a short-term and long-term strategy are needed. A short-term strategy would focus on the more descriptive aspects of the questions so that a “picture” of enabling services can be developed as the foundation for designing more intensive research efforts. The short-term strategy would include both efforts to analyze secondary data and information and efforts to more prospectively consider issues related to enabling

services. The short-term strategy would first operationalize strategies for allocating resources and develop data strategies.

We believe that the Office of the Assistant Secretary for Planning and Evaluation (ASPE) is an appropriate though not necessary office to lead and coordinate this effort, working with the health agencies of DHHS because of the cross-cutting nature of some of the questions and proposed strategies to address them. ASPE, through its evaluation planning (and coordination) efforts could also help assure that issues related to enabling services are built into various evaluation and research activities. ASPE could also examine current data collection efforts both by programs and broader survey work to determine how to assure appropriate focus on enabling services issues. For example, building questions on access and use of enabling services in population-based studies of health care and disparities in health status. Given, the limited resources like to be available to examine enabling services issues, it will be important to be opportunistic. It was clear from discussions with the Roundtable, their agencies and programs have opportunities within their planned work to consider enabling services more specifically than is currently being done.

Areas where focus on enabling services might be enhanced include: studies on current conditions such as the Medicaid asthma initiative; clinical outcomes work conducted by the Bureau of Primary Health Care; research supported by the Maternal and Child Health Bureau related to children with special health care needs; AHCPR sponsored work on primary care, evaluations of the State Children's Health Insurance Program; and examinations of issues of medical or health homes, cultural competence, and disease management strategies.

The five issue areas used to explore enabling services as part of this effort help to identify key research areas

The prior issues-based discussions identified numerous questions within each of our issue areas that require either better definitions and/or research to provide better answers. A brief summary of some of the key questions are provided in the following table:

Exhibit 2: Key research areas

Issue Area	Key research related areas
#1 : Definitions	<ul style="list-style-type: none"> · Approaches to address what is meant by and included in enabling services ▪ Common definitions and/or typologies · Patterns of enabling services/bundling issues
#2: Determining Needs	<ul style="list-style-type: none"> · Approaches to determining individual needs for enabling services · Development of population-based needs assessment methods ▪ Approaches used to plan services, determine benefit packages, and payments (both capitated and fee for service)
#3: Provider and Delivery System Issues	<ul style="list-style-type: none"> • The current provider profile and how it is changing ▪ The role of traditional safety net providers and how their role is changing · The implications of changes such as Medicaid managed care and increased presence of disease management companies and strategies · Differences in costs and effectiveness of different providers · Differences between in-house services or contracting for services
#4: Paying for Services	<ul style="list-style-type: none"> · How enabling services are currently paid for in the public sector including what services are covered by what payer; the basis for payment; and differences in costs and payment for services ▪ The role of insurance versus grant programs · Issues for different populations and/or disease/conditions
#5: Costs and Effectiveness	<ul style="list-style-type: none"> ▪ Information needed to determine the basis for examining issues of costs and effectiveness (patterns of utilization of enabling services for specific populations or cases) · “Unit” and case-specific costs · What enabling services are associated with better outcomes

Issues of what to look at require determining what questions need to answer and why

As the summary table above and Exhibit 1 on stakeholder concerns demonstrate, there are a large number of questions related to enabling services that continue to be asked. Some of these concerns are being addressed but often in indirect ways or not readily

accessible to interested parties. Our roundtable discussion demonstrated that point as various participants brought knowledge to the discussion in areas that others were not aware. Often, the references to the research was also vague and difficult to identify specific citations.

In order to identify priorities in setting a research agenda, it is important to determine what one needs to know and for what purpose. There are several ways to look at how to set priorities and begin to better address the continuing sets of questions related to enabling services. We recommend that the following be used as criteria for selecting and supporting potential studies.

1. **Addressing: the basic needs for information about enabling services.** Our assessment suggests that there is a need for consistent definitions and methods of looking at enabling services. Good descriptive information on what enabling services are provided to which populations; who and how are these services provided; and how they are currently being financed are needed to gain a broader, comprehensive set of information on enabling services.
2. **Focusing on those issues of greatest concern to Federally supported programs that provide or finance enabling services.** There is major concern on the part of those federal agencies and programs that support programs for these populations and in particular, support the provision of enabling services. These concerns center on a better understanding of how current policies and changes are affecting the ability to provide enabling services. This perspective assumes that enabling services are effective in assuring access and/or better outcomes and that changes such as increasing use of managed care is having an impact on enabling services.
3. **Focusing on areas that would further the knowledge of the cost-effectiveness of enabling services.** Our review suggests that while many believe that enabling services are important, there is limited evidence about what works and why. There is, however agreement that in order to assure that enabling services are paid for, more evidence is required.

A strategy for designing and implementing studies of enabling services

The following describes potential study areas with a particular emphasis on those that can be more narrowly defined and carried out in the short-term. We also emphasize public sector programs and/or populations likely to be served by the public sector as the primary concern of ASPE. Examination of private trends and approaches are suggested as a way of learning what might be applicable to the public sector.

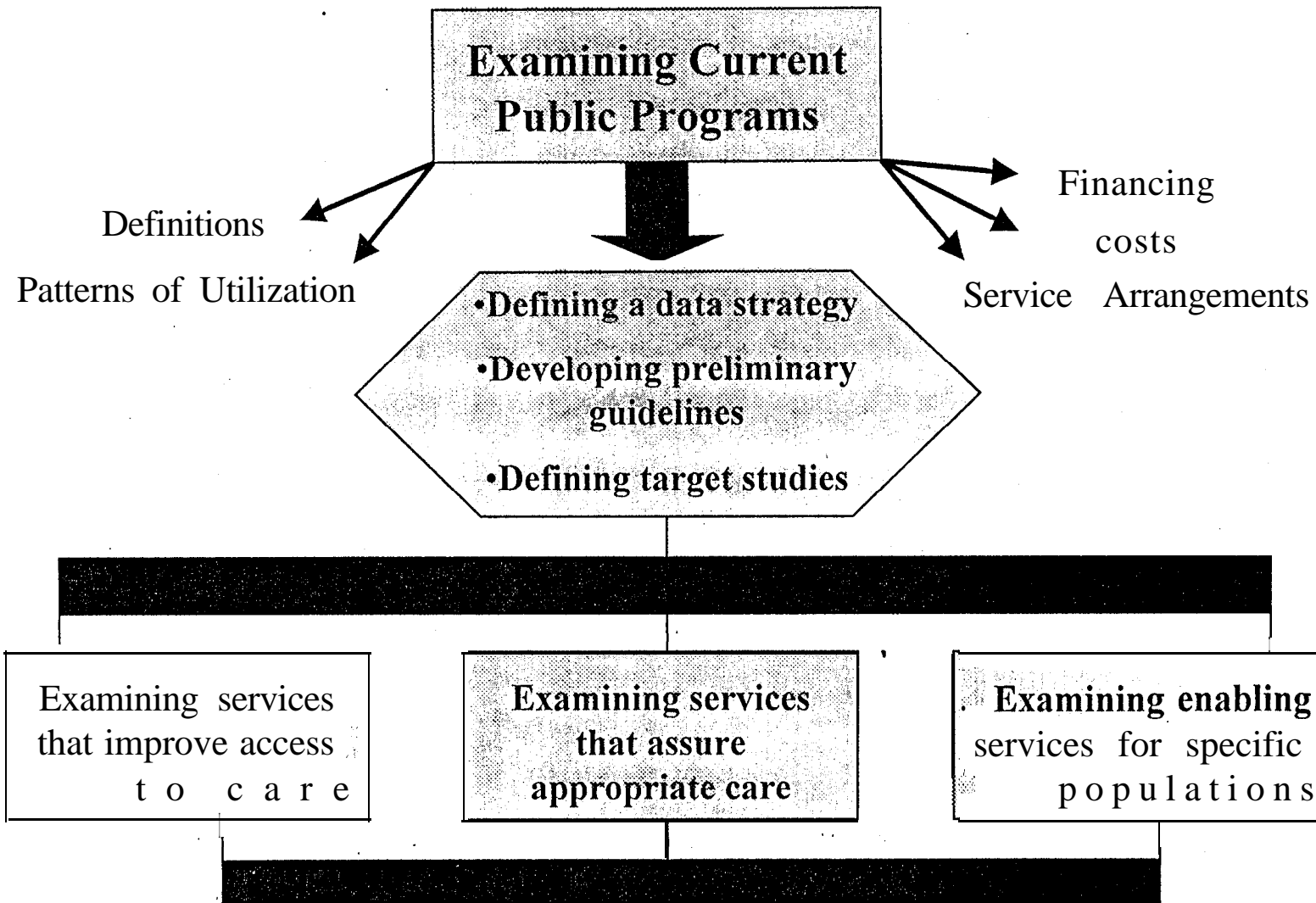
Exhibit 3 provides a schematic for considering a starting point for studies and how the various proposed study areas may link. The starting point is defined as the examination of current public programs. We believe a carefully designed study or studies as described below will yield a better basis for understanding enabling services by providing: definitions, patterns of utilization of services, how they are financed, some information on costs, and description of current and changing service arrangements.

The foundation of information provided by these initial efforts should yield:

- . A preliminary data strategy for collecting enabling services information on a continuing basis;
- Information that could be collected by modifying current surveys and other data collection activities;
- . Development of preliminary guidelines and standards for considering enabling services; and
- The basis for more targeted studies and a long term research agenda on efficiency and effectiveness.

The next stage of effort can then focus on targeted studies that examine specific enabling services and/or bundles of services and explore population or condition-based issues related to enabling services. During this same period, a more intensive long-term research strategy can be designed and implemented. This longer-term-strategy should be designed to be policy-relevant, providing more extensive data and results to support changes in approaches to financing and delivering enabling services.

Exhibit 3: Implementing a Research Strategy on Enabling Services,



The following discussion uses this approach to articulate potential studies to implement the strategy. Primary emphasis is placed on the first level of effort: examining current public programs..

Potential Study Area 1: Examining public sector programs that support enabling services

We propose that the starting point for research on enabling services is the **examination** of public sector efforts. These include both public insurance programs and a variety of grant programs that support or provide enabling services. This examination should address a number of key questions such as: How are enabling services defined? Who is paying for and/or arranging for which services? What do they cost? Who is getting those services? We believe that by looking at specific public programs **that** fund enabling services, basic descriptive information can be collected and assessed as the needed starting point in conducting more analytical studies of costs and effects. Developing common definitions and data collection approaches will enhance these efforts.

Ultimately the concern is that there be appropriate support to ensure the availability of enabling services. This area therefore focuses on a better understanding of what enabling services are currently being providing, some information on costs and what is being paid for now and allows for a more-grounded assessment of the gaps and issues that require new policy and program interventions. --

Three specific efforts are proposed to provide this information. Given potential timing and funding limitations, it is possible to fund various approaches that might cut across each of these individual areas..

1. Assess currently supported enabling services in Medicaid managed care contracts

A critical source of support for enabling services has traditionally been Medicaid programs. Because Medicaid is a state-based program and many of the potential enabling services that might be included in benefit packages are usually part of optional services that states may provide, there are a number of different patterns across the states.

Attachment 2 provides a detailed summary developed by the National Academy of-State Health Policy. We have abstracted the enabling services identified in that report by state and within each state for specific Medicaid populations. There are clearly different patterns of support for enabling services both across states and populations. The work by NASHP, however, does not show what is currently happening as a result of the major shifts to managed care contracting for various Medicaid populations.’

We propose that one or more descriptive studies be conducted to collect more detailed and current information. Several alternative approaches might be used. In each case, we are suggesting that rather than an all states study that would involve more time and resources than are available, studies be based on a sub-set of states. Each of these alternatives generally will require a “feasibility” effort to determine ~~the~~ availability of data and then the actual design and conduct of the effort. The currently fluid nature of services and program data in both insurance and grant programs necessitates this careful examination in order to ensure an appropriate design.

The various alternatives should provide the basis for answering the following questions:

- What enabling services do Medicaid programs pay for and how?
- . What are the parameters of given enabling services that help define ~~them~~?
- What is the nature of the ~~financing~~ arrangements?
- . What populations are receiving which services? What are the patterns of utilization?
- What are the delivery systems and approaches used to provide these services?
- What evidence is currently available about the “success” or effect of these services?

¹ Obviously, information would have to be verified for currency.

Alternative 1: Conduct a population-specific study across a set of states

This alternative would involve selecting a particular population or populations such as pregnant women, children with special health care needs or persons with disabilities as the focus. Selecting **pregnant women** and one of the other populations might be useful to examine differences related to managed care since in many states, the CSHCN and disability groups are less likely to be in managed care plans. A sub-set of six to nine states could be selected to explore the range of enabling services provided to the population. Preliminary data gathering would be required to determine what types of databases are available in the state before the actual detailed approaches could be worked out. Among the considerations in how to actually design the study are the status and approaches to managed care efforts and the implications for data availability including the current status of encounter and other types of data. The data issues will be a primary consideration in the ability to address all questions. Exploration of these data issues might also require working with the state and the contracted health plans as data are likely to vary by plans.

Alternative 2: Examining specific enabling services

Instead of selecting a population focus, this alternative would examine one or more enabling services to collect descriptive information across a sub-set of **states**. This approach could take a single service such as transportation or outreach and examine the various approaches as to how Medicaid finances and arranges for that particular service. This examination could provide good descriptive information and be a companion to a similar study across grant programs suggested below. This **information** is an important prerequisite for more in-depth examination of service options.

2. Examination of the various grant programs funded by HHS and how they address enabling services

This area is actually a companion to the Medicaid efforts but is potentially more complex because it involves a large number of Federally supported programs who may have a variety of grantees who actually provide or arrange for services. For the most part, the

major distinction in these programs is that the support is for actual service delivery or more generally to the organizations/providers that offer the services as opposed to an insurance mechanism. Additionally, there are a number of complexities that evolve from the differences among the various grant efforts and the effect that has on the types and availability of data. Two alternative approaches are suggested:

Alternative 1: Individual or cross-grant program efforts

There are a number of grant programs within the public health agencies of DHHS that support enabling services for various populations. Among these programs are: the various Ryan White programs, the Maternal and Child Health Block grant, other MCH programs, Community Health Centers and various special initiatives, CDC efforts including the Public Health Block grants and special programs, and SAMHSA efforts including the various block grants and special initiatives. Currently **there** is no aggregated source of information across these efforts. To fully assemble such a database is probably not a feasible **effort**. However it is critical to develop systematic approaches to data as well as a plan of implementation.

To address the task of developing good descriptive information on enabling services across the various grant programs, we recommend consideration of the following:

- A short term effort to collect general information from each appropriate grant program. Using a common protocol, a study could be designed to review written materials and interview Federal program managers to assemble an inventory.
- Convene representatives across programs to identify specific grant programs that can work together to design and support more field related studies of how enabling services actually are implemented. While the nature of individual grant programs varies, consideration of common approaches would enhance the ability to develop cross-cutting efforts and shared learning. This approach could also be used to encourage investments by individual programs in supporting specific enabling services.

Alternative 2: Linking a cross-grant effort to the Medicaid analysis

Another approach to consider is a geographically focused effort. This would take the form of a state-based effort, where a small set of six to nine states would be selected for analysis. The focus within each state would be on both Medicaid funding and on how the various Federal grant programs play out in each state. This study could use a **population-based** or (safety net) provider-based approach to examine such questions as:

- . How are enabling services provided?
- What is the relationship between Medicaid reimbursement and other funding sources in offering specific (enabling) services?
- . What are the issues, from the perspective of safety net providers, with regard to offering and/or supporting the provision of enabling services?
- From the perspective of consumers, how aware are they of enabling services, what difference do enabling services make in relation to accessing and appropriately using medical services?

3. Examination of State Title XXI programs and how enabling services are addressed

A focus on Title XXI is proposed for consideration as part of the evolving overall evaluation strategy for that new initiative. As the strategy is developed to evaluate Title XXI, we would recommend consideration be given to including enabling services questions within the context of the evaluation. The emphasis here would be to: determine what enabling services are included in benefit packages and then to explore the range of enabling questions we have already identified. Particular issues that might be emphasized would be to examine the relationships between the State CHIP program and other grant programs and/or safety net providers. Special emphasis could be place on looking at whether access to specific enabling services has improved or not as a result of the expansion of health insurance for children. Specific “best practices” studies on areas of greatest concern such as outreach could be supported.

Potential Study Area 2:. Second-stage studies of enabling services

This area is designed to move from the information gathered in the first study area which is likely to be more descriptive in nature to articulate a more detailed set of studies of enabling services that can begin to answer the questions of effectiveness and efficiency. An important activity that should be built into the Area 1 study or studies is a process for examining the information gained by the descriptive efforts in the context of the current policy environment to set priorities for this second set of studies. A hierarchy of needs for information on particular enabling services or a population-based approach may be used to guide the actual selection of studies to be designed and supported. •

As described to us, ASPE's key interest is on enabling services that support medical care and provide a link to other social services but do not include those services. The following **typology** of enabling services sorts those services by their primary objectives: improving access to medical and other services, helping people get the appropriate services, and improving the outcomes of medical/health services. While the actual placement of particular enabling services may need to be adjusted, consideration of the underlying purpose of a given enabling service appears to help thinking through approaches to looking at effectiveness and cost related issues. We believe that this approach to thinking about specific studies will help focus the purpose of such studies and allow for setting priorities on what to study.

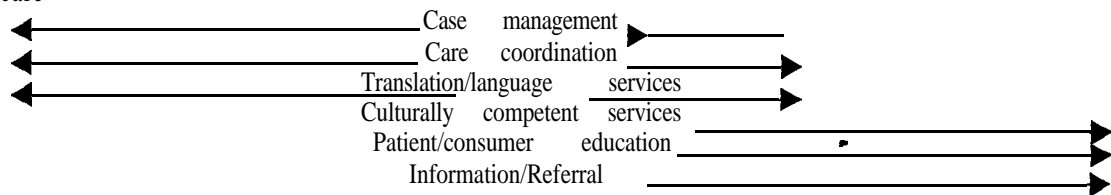
ENABLING SERVICES TYPOLOGY

**Services that primarily
improve access**

**Services that help
assure that “appropriate”
care is received**

**Services that
enhance outcomes**

Transportation
Outreach
Childcare



Environmental risk reduction
Housing, food, clothing
Assistive technology, home
modification, DME
Nutritional counseling
Respite care
Homemaker assistance

Review of this **typology** suggests that the services identified in the first two categories are the primary interest of ASPE at this time. The services in the third area are often considered either health services or social services and reflect services case managers and others may try and arrange for a given patient. Our discussion of disease management is a potential way of addressing the last area. This area may be more appropriately addressed in the long-term research strategy.

We recommend that the following three categories of studies be developed, using information from studies in area 1 to better define them.

1. **Examining enabling services that address barriers to access**
2. **Examining enabling services that help assure appropriate care is received**

We have grouped these together for discussion and to focus on the types of approaches and considerations that need to be addressed. The primary objective of any of these studies will be to begin to understand the effect individual and/or sets of enabling services have on these two objectives. Studies in this area could provide useful information on what works and under what circumstances. This may be an important area for best practices efforts.

An interesting example of one approach to this has been developed in a study of approaches to address the language barrier was developed by John Hornberger at Stanford University.² His approach examines the range of services/approaches to addressing the language barrier for providing health care services. Using a taxonomy of methods and a set of cost categories for the methods, he examined how the services are provided in various settings. He was able to analyze the costs of the various methods, using data from specific settings and provide information comparing the costs of various methods. This basic approach offers potential application to exploring various enabling services.

² set up as footnote – not sure of format: John Hornberger, Evaluating the Costs of Bridging Language Barriers in Health Care, Journal of Health Care for the Poor and Underserved, Vol 9, s26-39. Supplemental 1998.

3. Examining how enabling services are provided for specific populations

We propose that consideration be given to studying the approaches used by disease management to better understand the role of enabling services. Such an examination would extend to all three objectives articulated in Exhibit 4.³

Given the definition of disease management as “a comprehensive, integrated system for managing selected patient populations across the health care continuum by using a variety of tools and interventions to improve the quality and reduce the cost of care,”⁴ a more detailed exploration of disease management activities might provide very focused information on a range of issues regarding enabling services. As the attachment suggests, disease management models as being applied to a variety of chronic conditions and populations including asthma, diabetes, AIDS/HIV, hemophilia and is currently being pursued as a viable approach for addressing the needs of Medicaid and Medicare populations. This study could explore non-clinical interventions and their relationship to outcomes that are being used by disease management including health education, case management and prevention strategies into their models. Some of the work reviewed in the attachment provides a basis for thinking’ about the parameters of such an effort.

Additional efforts in implementing the overall strategy

The strategy we are proposing includes several steps that we think will help enhance the knowledge base on enabling services in the long term and help answer the varied questions that are currently being asked. In this vein, we offer the following recommendations.

1. A cross-program effort to develop better data collection on enabling services should be supported.

This effort, briefly addressed earlier in the paper, is premised on the assumption that there are various federal programs that have a common interest in better understanding

³ Attachment XX provides more detailed information on our exploration of disease management

⁴ (Bernard & Frist, 1998).

enabling services. It was certainly clear from our Roundtable discussion that there were common interests across the various programs represented at the table and limited sharing of currently available information. A working group could begin to explore common approaches to information and design of studies. An important starting point might be review of current program **information** systems and surveys used by the programs to determine how small modifications might enhance current information. This review might also include a limited abstracting and analysis effort of current databases as well as a compilation of any related special studies. In addition, the group might determine . approaches to sampling within their universe of programs. This cooperative effort might also expand the availability of resources to support investigations and data collection.

2. Interested groups should be convened to develop strategies for guidelines/standards of practice and review of best practices in enabling services.

Programs and the broader set of stakeholders are looking for guidance and information on making decisions about which enabling services to support and what the best approaches are to supporting them. Witness the recent concerns about how to effectively outreach in the expanded children's health insurance initiatives. This effort could be a public/private initiative that creates a forum to identify best practices and to help articulate guidelines that might be useful in the field. The group could also serve as a technical resource for the review of information from the first phase of studies and provide guidance on the second phase of studies.

3. An effort to develop a long-term research agenda on the costs and effectiveness of enabling services should be supported.

Based upon the current state of knowledge on enabling services and the guidance we received that there were extremely limited funds, it is our view that the specification of a detailed long-term research agenda may be premature. We believe that some of the descriptive work we are proposing would greatly enhance the utility of a policy-oriented research agenda on enabling services. Support for more long-term research on costs and effectiveness is clearly needed. However, recognition of limited funding and unclear

priorities, leads us to believe that a very focused agenda might be considered by DHHS's policy research agency, the Agency for Health Care Policy and Research. Once there are clear definitions, baseline and descriptive information, and clear policy focus, the setting of priorities for a funded initiative of either specific studies or investigator initiated research would be appropriate. Such efforts should include participation of the other DHHS agencies involved more directly with delivery service and population issues.

Both the short and long-term strategy options that are proposed in this paper will require further review and consideration. Based on our experience during this effort, we think a small working group across the interested and affected DHHS program/agency offices should be convened to support ongoing efforts related to enabling services. This group should be convened to review the findings and recommendations of this report, develop priorities, and set an agenda that can be funded to initiate more coordinated and focussed efforts on examining enabling services issues. Review of current resources to support work in the area of enabling services needs to be undertaken to determine the potential scope of activities that can be supported both intramurally and through possible use of contracting.

The issues of enabling services are important as efforts to improve the impacts of health services continue, as publicly supported insurance programs are expanded, as efforts to address disparities are developed, and as managed care efforts are reexamined. The role enabling services play in both enhancing access to health services and in assuring those services are provided are important for future policy decisions and investment strategies.

ATTACHMENT 1

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BIBLIOGRAPHY

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ATTACHMENT 2

ENABLING SERVICES IN STATE MEDICAID PROGRAMS

National Academy for State Health Policy
Scope of Capitated Services Risk-Based Contracting
Prepared January 1997

State Medicaid Programs Inclusion of Enabling Services by various populations

	AL	AZ	CA	CO	CT	DE	DC	FL	GA	HI	IL	IN	IA	KS	MD	MA	MI	MN	MO
Targeted Case Management	1,2,3,4,5,6,7,8,(d)	1,2,3,4,5,6,7,8,10(c)	1,2,3,4,5,6,7,8	1,2,3,5,6,7,8	1,2,3	1,2,3,6,7,8,9	6	1,2,3,4,5,6,7,8		1,2,3,9		1,2,3	1,2,3	1,2,3	1,2,3				
Home Health Services	1,2,3,4,5,6,7,8	1,2,3,4,5,6,7,8,10	1,2,3,4,5,6,7,8	1,2,3,5,6,7,8	1,2,3	1,2,3,6,7,8,9	6	1,2,3,4,5,6,7,8	1,3,6,7	1,2,3,9	1,5	1,2,3	1,2,3	1,2,3	1,3,5,6,7	1,3,5,6,7,(f)	1,2,3,6,7	1,2,3,4,5	1,2,3,10
Full Benefit for Extended Care Services	1,2,3,4,5,6,7,8(e)	1,2,3,4,5,6,7,8,10			1,2,3	1,2,3,6,7,8,9(a)	6	1,2,3,4,5,6,7,8	1,3,6,7	1,2,3,9	1,5	1,2,3	1,2,3	1,2,3	1,3,5,6,7			1,2,3,4,5,(a)	1,2,3,10
Indigenous Community Outreach Workers	1,2,3,4,5,6,7,8(f)				1,2,3	1,2,3,6,7,8,9													
Outreach Workers for Home Follow-up Visits					1,2,3	1,2,3,6,7,8,9	6			1,2,3,9									
Translation On Site		1,2,3,4,5,6,7,8,10			1,2,3		6			1,2,3,9					1,3,5,6,7			1,2,3,4,5(b)	1,2,3,10
Translation Off Site		1,2,3,4,5,6,7,8(k)	1,2,3,4,5,6,7,8,10	1,2,3,5,6,7,8	1,2,3		6			1,2,3,9			1,2,3						1,2,3,10
Non-emergency Transportation (e.g., cab, bus)	1,2,7,8	1,2,3,4,5,6,7,8			1,2,3		6			1,2,3,9	1	1,2,3		1,2,3				1,2,3,4,5(c)	1,2,3,10
Other (specify)							✓												1,2,3,10(c)

	MD	NE	NV	NH	NJ	NY	NC	OH	OK	OR(a)	PA	RI	SC	TN	TX	UT	VA	WA	WI(a)
Targeted Case Management	1, 2, 3 (b)	1, 3, 5, 6, 7, 8, 10			1, 2, 3, 5, 6, 7			1, 2, 3, 6, 7	1, 2, 3		1, 2, 3, 5, 6, 7, 8	1, 2, 3, 9					1, 2, 3, 5, 6, 7, 8	6, 7, 8 (e)	1, 2, 3, 4, 5, 6, 7, 10
Home Health Services	1, 2, 3	1, 3, 5, 6, 7, 8, 10		1, 2, 3	1, 2, 3, 5, 6, 7	1, 3, 5, 7	1, 2, 3, 6	1, 2, 3, 6, 7	1, 2, 3	1, 2, 3, 4, 5, 6, 7, 8, 9, 10	1, 2, 3, 5, 6, 7, 8	1, 2, 3, 9		1, 2, 3, 5, 6, 7, 8, 9	1, 3 (a)	1, 2, 3, 5, 6, 7	1, 2, 3, 5, 6, 7, 8	1, 2, 3, 6, 7, 8	1, 2, 3, 4, 5, 6, 7, 8
Full Benefit for Extended Care Services		1, 3, 5, 6, 7, 8, 10			1, 2, 3, 5, 6, 7	1, 3, 5, 7	1, 2, 3, 6	1, 2, 3, 6, 7	1, 2, 3		1, 2, 3, 5, 6, 7, 8	1, 2, 3, 9					1, 2, 3, 5, 6, 7, 8	1, 2, 3, 4, 5, 6, 7	1, 2, 3, 4, 5, 6, 7, 10
Indigenous Community Outreach Workers		1, 3, 5, 6, 7, 8, 10				1, 3, 5, 7										1, 2, 3, 5, 6, 7			1, 2, 3, 4, 5, 6, 7, 10
Outreach Workers for Home Follow-up Visits		1, 3, 5, 6, 7, 8, 10			1, 2, 3, 5, 6, 7	1, 3, 5, 7					1, 2, 3								1, 2, 3, 4, 5, 6, 7, 10
Translation On Site		1, 3, 5, 6, 7, 8, 10			1, 2, 3, 5, 6, 7	1, 3, 5, 7, 6	1, 2, 3, 6	1, 2, 3, 6, 7		1, 2, 3, 4, 5, 6, 7, 8, 9, 10	1, 2, 3, 5, 6, 7, 8	1, 2, 3, 9			1, 2, 3		1, 2, 3, 5, 6, 7, 8	1, 2, 3, 4, 5, 6, 7, 10	
Translation Off Site		1, 3, 5, 6, 7, 8, 10			1, 2, 3, 5, 6, 7	1, 3, 5, 7	1, 2, 3, 6		1, 2, 3	1, 2, 3, 4, 5, 6, 7, 8, 9, 10	1, 2, 3, 5, 6, 7, 8	1, 2, 3, 9			1, 2, 3		1, 2, 3, 5, 6, 7, 8	1, 2, 3, 4, 5, 6, 7, 10	
Non-emergency Transportation (e.g., cab, bus)		1, 3, 5, 6, 7, 8, 10				1, 3, 5, 7 (d)			1, 2, 3	1, 2, 3, 4, 5, 6, 7, 8, 9, 10		1, 2, 3, 9					1, 2, 3, 5, 6, 7, 8	1, 2, 3, 5, 6, 7, 8	1, 2, 3
Other (specify)							1, 2, 3, 6 (a)	1, 2, 3, 6, 7 (b)		4, 5, 6, 7, 8 (i)									

♦ Populations

- 1 = AFDC
2 = Poverty level pregnant women
3 = Poverty level children
4 = Aged, nursing home care
5 = Aged, non-nursing home care
6 = SSI children
7 = SSI adult, community
8 = SSI adult non-community
9 = 1115 expansion
10 = Other (excluding GA)

Notes: Unless otherwise specified, the note refers to all populations the state covers

AL: (a) Maternity waiver program serves pregnant women regardless of eligibility category.

AZ: (a) ALTCS covers up to 300% of SSI for populations 4 and 5.

(b) Family planning is required to be covered by plan, but if a plan chooses not to provide certain services, it may subcontract, but must pay the subcontractor.

(c) EPSDT only.

(d) EPSDT and ALTCS services only.

(e) In place of hospital care for acute care (AHCCS) and full benefits for ALTCS services.

(f) Up to 90 days for acute care (AHCCS).

(g) Full benefits for enrollees in ALTCS.

(h) This service is only provided through the ALTCS program for the developmentally disabled by the Department of Economic Security, Division of Developmentally Disabled.

(i) Personal care ALTCS only.

(j) This is an ALTCS service on some Indian reservations.

(k) Not formalized. If a person needs a translator, arrangements are made.

CA: (a) Population 10 = medically indigent and refugees.

(b) Depends on the individual contract.

(c) These services are provided if not available from other programs or agencies.

(d) Sixty days.

CT: (a) This state does not have a separate category for SSI children.

DE: (a) Except for private duty nursing.

DC: (a) Any medically necessary service required.

(b) Limited use of telephones

FL: (a) Separate risk contract only for PCCM enrollees; HMO enrollees receive these benefits through the HMO.

(b) For population under 21 years of age.

(c) Plan option.

(d) For plan with Long-Term Care Risk.

HI: (a) Enrollees are not allowed to go out of the plan for these services. The family planning access requirement does not apply to the Hawaii waiver.

IA: (a) Optional service.

IL: (a) One a limited basis.

(b) Under age 21.

KS: (a) Except for prescriptions for family planning and mental health; these services are carved out of the program.

MD: (a) For children.

MA: (a) Single contractor only for those not in HMOs.

(b) For HMO enrollees only.

(c) Two of nine MCOs pay for prescription drugs.

(d) up to \$1,500.

(e) Exams only.

(f) Only as a substitute for acute inpatient care.

(g) Optional.

(h) Enhanced case management for SSI; Medicare co-payments and deductibles for elderly.

MI: (a) MI includes in their SSI population SSI beneficiaries over the age of 65.

(b) For enrollees in PCCM program.

(c) For enrollees in the clinic plans; includes methadone treatment.

(d) For enrollees in the HMO program; includes methadone treatment.

(e) Hospice, condoms, orthotic devices, and medical supplies,

MN: (a) Excluding waived services.

(b) In contract.

(c) HMO option.

MO: (a) MO is not a 1634 state. SSI individuals are included in the target population and not as a separate category; population 10 = refugees and children in state custody.

(b) Services are covered for those under age 21.

(c) Telecommunications device, TDD, braille, or audio.

MT: (a) Population 3, if service is in package.

(b) Only for high-risk pregnant women.

(c) Private duty nursing only,

(d) Hospice.

NE: (a) Population 10 = state wards.

(b) MHSAS/RTC.

NH: (a) Limited.

(b) Screens,

NY: (a) Plan option.

(b) Providers bill the state; the state bills the plan.

(c) Option in year one.

(d) County option.

NC: (a) Member services, care coordinators.

OH: (a) Unless they contract with a family planning provider, it is mandatory.

(b) Member services, toll-free hotline.

OR: (a) Population 10 = children in state care.

(b) The separate contract serves 25% of population.

(c) For somatic mental health only.

(d) Acute hospital care only; not residential.

(e) In one county only.

(f) Outpatient and methadone.

(g) Excludes mental health drugs.

(h) As of 10/1/96 only dental care organizations will be able to contract to provide dental care services; is currently an option for all contractors.

(i) Exceptional needs care coordination.

PA: (a) First 30 days.

RI: (a) Enrollees may not go out of network for these services. Plans must have adequate

- access to provide confidential family planning to teens.
- TN: (a) If cost effective,
(b) Under the age of 21.
(c) Cost-effective alternatives.
- TX: (a) Population 1; contractors must cover this service for those under age 21.
(b) Population 1; contractors must cover this service for those 21 years old and over.
- UT: (a) Coverage is required, due to a grandfather clause, in the contracts of the two original contractors. New contractors are not required to cover this service. For the two original contractors, coverage is a full benefit in the contract.
- VA:** (a) Private duty nursing under EPSDT only.
- WA:** (a) Administered by the Mental Health Division, no Medicaid involvement.
(b) Dental and mental health prescriptions paid fee-for-service.
(c) EPSDT only.
(d) Population 4; eyeglasses and lenses are covered under FFS only.
(e) For SSI only.
(f) Private duty nurse only.
- WI: (a) Population 6 covers those over 15 years of age; population 10 = children with severe emotional problems.
(b) Population 10; mental health coverage only.

ATTACHMENT 3

DISEASE MANAGEMENT

Disease Management

A hybrid disease management model may serve as a useful conceptual framework for the adoption of both public and private sector **coverage for** enabling services. Disease management is defined as “a comprehensive, integrated system for managing selected patient populations across the health care continuum by using a variety of tools and interventions to improve the quality and reduce the cost of care.” (Bernard & Frist, 1998). With its potential for cost savings and improved outcomes, disease management has become an attractive model for addressing chronic, complex, and costly conditions and diseases in populations. Disease management has traditionally been applied to chronic conditions such as asthma, diabetes, AIDS/HIV, and hemophilia and is currently being pursued as a viable approach for addressing the specific needs of Medicaid and Medicare populations. While disease management companies typically focus on proactively identifying and providing the clinical interventions needed to manage a disease, some disease management companies realize the importance or impact that non-clinical interventions have on outcomes, and are therefore beginning to include health education, case management, and prevention strategies in their models. This presents a unique opportunity for examining whether a hybrid model can be developed fusing disease management and enabling services concepts and characteristics. The following sections describe: traditional disease management approaches; disease management applied to the Medicaid population; and a proposed hybrid disease management/enabling services model.

A. Traditional Disease Management

Because of the potential for lowered costs and improved outcomes, traditional disease management models have targeted chronic conditions such as asthma, diabetes, AIDS, and hemophilia. A 1997 Lewin Group report chronicles the different forms that disease management models can adopt: a carve-out model; a carve-in model; a comprehensive approach, or a focused approach. In a carve-out model, the disease management company (DMC) provides services “in-house” and assumes all financial risk in doing so whereas in a carve-in model the DMC utilizes external providers (e.g., MCOs, physicians) to deliver services. Often, a managed care company may already have its own disease management program and therefore not rely on DMCs. The Lewin Group report found that the number of HMOs using disease management carve-out programs have, steadily increased for diabetes and AIDS. More recent developments, however, find managed care organizations combining their in-house capability for disease management with services from contracted out vendors (especially pharmaceutical services). (Disease Management News 3(24), 1998).

The Lewin Group found that disease management programs may either be focused or comprehensive in the breadth of services that they offer. A focused disease management program is aimed at addressing a specific condition using a specific product or service whereas a comprehensive program may involve a wide spectrum of services including prevention, education, case management, and treatment geared at one or a variety of conditions. Depending on the model used, the mix of providers (PCPs, specialists, nurse educators, case managers) needed will also vary. (TLG, Medicaid Reform in Florida, 1997):

Applications of disease management models vary greatly by the type of disease targeted and the objective to be achieved. The Lovelace Health Systems' disease management model represents the key concepts traditionally used in disease management models.

Lovelace Health System, in New Mexico, recently established an episodes of care (EOC) program for its pediatric asthma patients. Although their program targets asthma patients, the techniques used are pervasive across different programs and include: a multi-disciplinary team of health care professionals; the development of practice guidelines; the identification and provision of supplemental access entry points; the education/training of patient, provider, and caregiver; and the measurement of processes and outcomes (Marosi, et al 1998).

Medicaid managed care programs have recently begun to incorporate disease management approaches. As of 1988, different states like Florida, Georgia, and Texas were applying disease management to chronic conditions commonly found in the Medicaid population (e.g. asthma/ diabetes, HIV/AIDS, hemophilia, and others). Among the obstacles they found in implementing these programs were: inadequate reimbursement; lack of patient compliance; the transient nature of the Medicaid population; cultural/educational/linguistic barriers; the existence of comorbidity in the Medicaid population that requires a more elaborate disease management model; and persons dually Medicare and Medicaid eligible experiencing increased barriers to accessing disease management programs.

While States are taking preliminary steps in implementing disease management approaches, consensus on whether disease management companies need (or want) to manage all aspects of a disease, both clinical and non-clinical, has not been reached. It is in this discussion that the applicability of disease management as a useful model for enabling services may be apparent. Using a disease management model that addresses the multidimensional needs of an individual or disease state can address many of the issues related to the fragmented care and service delivery that results when dealing with complex conditions/diseases. If research can demonstrate how cost effective enabling services are as they relate to specific conditions, diseases, or with certain populations, it is more likely to be considered by both public and private payors.

A disease management model most directly applies to assuring appropriate care is received and enhancing outcomes. Disease management approaches operate by integrating all necessary services within its delivery care model. The team based provider and service approach used in disease management mirrors what case managers do to facilitate the delivery of appropriate care. In fact, there typically exists collaboration between disease management personnel and case managers in the health care delivery setting (Bernard & Frist, 1998). An added benefit of disease management approaches is the ability to measure tangible outcomes. In dealing with chronic conditions, the end goal is to improve outcomes, decrease costs, and maximize functioning. Disease management is the fairly predictable, evidence-based, outcome-oriented, proactive management of complex, costly, and chronic diseases/conditions. Clinical data warehouses and patient

registries are essential to disease management for tracking patients and outcomes and sharing information among stakeholders.

Disease management literature describes the five key principles of disease management (Zitter, M. 1997). These steps may provide further direction and guidance for the development of strategic objectives for enabling services research:

1. Disease management should exhibit an understanding of the disease process (disease mapping) and what are the “drivers of cost.” Identifying the “drivers of cost” for enabling services has been an uphill battle, however, the importance of doing so is paramount. Researchers need to define what the direct and indirect costs associated with providing enabling services are and whether/which approach& used in disease management can be used.
2. Disease management should ensure that diagnosis and treatment is driven by the demands of the disease not by access to reimbursement. Reimbursement of enabling services has been a patchwork of public and private payers with great variation across states, populations, and programs. In this sense, reimbursement has served as a barrier to offering enabling services. By focusing on the ability of enabling services as a necessary mechanism for achieving the full benefit of an intervention, justification for reimbursement should follow.
3. Disease management should include the provision of educational interventions for all key stakeholders; patients, families, providers, etc. Patient education is. an important component in both disease management and enabling services. Education as an enabling service should mirror the disease managementmodel and be applied to providers, payers, families, and the like as well.
4. Disease management models should manage health care across the full spectrum of health care settings. Enabling services is typically not limited to a single health care setting and understands the importance of involving all components of the health system in ensuring access to care, appropriateness of care, and improved outcomes.
5. Disease management should fund mechanisms that identify or support cost-effective interventions. There exists a scarcity of funding to study and identify cost-effective enabling services. The studies that exist are limited to only a prescribed set of services delivered in particular settings by certain types of providers.